

MINUTES OF THE
JOINT HEALTH AND HUMAN SERVICES APPROPRIATION SUBCOMMITTEE
Monday, February 9, 2004, 2:00 p.m.
Room 131 State Capitol

Members Present: Sen. Sheldon L. Killpack, Committee Co-Chair
Rep. Jack A. Seitz, Committee Co-Chair
Sen. Paula Julander
Rep. J. Stuart Adams
Rep. Calvin G. Bird
Rep. David Litvack
Rep. Rebecca Lockhart
Rep. Roz McGee
Rep. Mike Thompson

Members Excused: Sen. Leonard Blackham

Staff Present: Spencer C. Pratt, Legislative Fiscal Analyst
Thor Nilsen, Legislative Fiscal Analyst
Norda Shepard, Secretary

Public Speakers Present: Joyce Dolcourt, Chairman, Coalition for People with Disabilities
Kris Fawson, Exe. Director., Legislative Coalition for People with Disabilities
Debbie Holt
Wendy Bonhan
Mary Alice Nielsen
Eric W. Bjorklund, President, Utah Youth Village
Shauna O'Neil, Director, Salt Lake County Aging Services
Albert Albrecht
Gaylord McCallason
Rich Connly, Board Member, Utah Association of Area Agencies on Aging
Richard Brown, Volunteer Ombudsman
Maureen Johnson
Barbara Dye
Ken Brown, Chairman, State Board of Aging and Adult Services
Pearl Rex Hartzell
Bill Cox, Utah Association of Counties
Michael Cragun, Utah Association of Counties
Jack Tanner, Executive Director, Utah Behavioral Health Care Network
Pat Fleming, Director, Salt Lake County Division of Substance Abuse Services
Stephen Unopulos
Deanna Lee
Rebecca Mason, Executive Director, Carbon County Retirement Volunteer Program
Max Young
John Harbert, Utah Association of Community Services
Kate McConaughy, Executive Director, Work Activity Center
Dr. David Christensen
Susan Reed
Suzanne Cunningham
Norma Gonzalez
Vicky Cottrell Executive Director, NAMI Utah
Stewart Ralphs
Asha Parehk, Director, YWCA
Terri Capener
Jean Pfaetz

A list of visitors and a copy of handouts are filed with the committee minutes.

The meeting was called to order by Co-Chair Killpack at 2:02 p.m.

1. Public Testimony Regarding Department of Human Services

Co-Chair Killpack reminded those who were signed up to comment that there would be a limit of five minutes for each testimony. He stated the committee would like to hear from as many as possible which necessitated the five minute limit.

Joyce Dolcourt, Chairman, Legislative Coalition for People with Disabilities, distributed a fact sheet listing the concerns of the coalition and a letter to the committee. She stated there are three principle issues that need to be addressed. She said the issues are the portability project which allows individuals to move between the ICF/MR system and home and community based services which has been on hold for two years; the provider reimbursements need an adjustment; and the funding for the waiting list. She indicated that without new funding for FY 2003 and FY 2004 the waiting list has grown to 1,919 people.

Kris Fawson, Executive Director, Legislative Coalition for People with Disabilities, stated that Julia Pierce and her son Dallon had been here to testify but Dallon became nervous and needed to leave so Ms. Fawson read a letter from Mrs. Pierce concerning her son. The letter stated that Dallon, who is 13, has been on the waiting list for eleven years for respite and family support. Dallon had an illness when two years old that left him with seizures. He functions at about a 2 or 3 year age level and is unable to talk. He needs twenty-four hour supervision. Mrs. Pierce asked for funding for respite and family support. Ms. Fawson also related a story of a family with two children with extremely severe disabilities who needed placement immediately because the father had Alzheimers and was being placed in a nursing home and the mother was dying of cancer. She stated that is the kind of situations this Division sees and the issues talked about here are about people's lives falling apart.

Debbie Holt stated she is a single parent with a 21 year old down syndrome son and has not had any help with her son at all. She indicated her son will graduate from Jordan Valley School soon and she will need to find other means to take care of him while she is working. She said she would have to sell her home, give up her job or find other means to take care of her son. She said DSPD needs funds to take care of people like her son.

Wendy Bonhan introduced her son, Garret. She said Garret will soon be aging out of the education system and is on the waiting list for services with DSPD. She indicated that Garret is mentally retarded and has personality traits that fall into the Autism spectrum. She said he is active and curious and is not one to sit and watch TV. He works, under supervision, at KenCraft. She said that once he turns 22 there will be no more help unless there is more funding for the waiting list.

Mary Alice Nielsen said she is the mother of a 35 year old disabled son who has had epilepsy since birth and has mild mental retardation. She said he has suffered a mild stroke due to medication problems and has had brain damage. She indicated he has been on the waiting list with DSPD for twelve years. She said she is 72 years old and is concerned about her son's future. She said she would like him to have experience with support services while she is still around to help him adjust. She said this is not about her, but about her son and others who are on the waiting list. She said she believes the community could do better. She distributed cards with a "Silver Ribbon" pin to committee members.

Eric W. Bjorklund, President, Utah Youth Village, a charity which takes care of troubled children in Utah, stated he was here on behalf of the provider's association. He distributed a handout showing two report cards typical of youth who come into the program. The cards show the difference between the 9th grade GPA of 0.614, and after being in the program, the 11th grade GPA of 3.372. This student is now a successful para-legal in Salt Lake. He said this is

an example that service providers do a good job to help problem children learn how to function to be good students and citizens. He said with the cost of business is continually going up and with no increase in provider's reimbursements, it makes it a very difficult atmosphere in which to provide good services.

Shauna O'Neil, Director, Salt Lake County Aging Services, said it was a privilege to talk about the state grandparents and great-grandparents and their needs. She indicated the mission of aging services is to help families keep their loved ones at home. She said most of these services are simple, such as day lunches, in-home services, transportation to doctor's offices, and investigation of abuse in nursing homes. She said these simple but critical services help to keep a family together and can help relieve the great pressure on families trying to care for their elderly loved ones. She distributed and read a letter from Cheryl Wilson, a care giver, which tells the impact of these services on the senior citizens who receive them.

Albert Albrecht, said he was speaking on behalf of aging services alternative programs. He said he was a caretaker for his wife and they have been fortunate in receiving services of the alternative program which has allowed meals-on-wheels, light house keeping, help with her showers and other physical care. He said the program is also a source of direction and helpful information. He said he would hate to think of the hardship they would have if funding was not available.

Gaylord McCallason stated he is retired from the United States Air Force and a volunteer for aging services senior transportation. He listed other areas where he has been a volunteer and grown from his service, but indicated that what he is doing now is really where the rubber hits the road. He said he was convinced that if senior transportation was not available there would be undue suffering and unnecessary early deaths because of lack of the proper medical attention they require. He said the recipients of this service are truly appreciative and always indicate their thanks to him.

Rich Connly, Director of Aging Service Davis County, said he was here to represent the Utah Association of Area Agencies on Aging, of which there are twelve within the state. He explained that the association is concerned that by 2007 those over 60 will pass the number of those in the state that are school age. He said plans need to be made for the aging population. He said there are already waiting lists for some services and some services have been cut. He voiced concerns about funding for the ombudsman program, nutrition programs, personal care, support to care givers and transportation. He said that volunteers are the backbone for all of these services but funding is still necessary.

Richard Brown stated he and his wife have been volunteer ombudsman for eight years. He indicated they get great satisfaction in knowing they are making a difference in the lives of those in nursing homes. He said there are 3,269 beds in nursing facilities in Salt Lake County with one paid ombudsman and 11 volunteers, many covering multiple homes. He indicated the program needs a lot more help.

Maureen Johnson introduced her husband, Bill, who is suffering from Alzheimers. She described how his disease has affected her husband and herself as his care giver. She indicated he attends the senior activity center in Orem three days a week. She said she is allowed 21 days of respite care a year. She said unless you deal with a person with this disease on a day to day basis, you don't understand how taxing it can be on the care givers. She said Bill has two college degrees and it is the saddest of diseases to watch your loved one slowly go away. She said there is a need for increases in in-home and care giver programs.

Barbara Dye displayed a "Dorothy Barbie" doll which said "we aren't in Kansas anymore." She said she is not poor, she can do whatever she wants on \$600 a month. She said she was only asking to have the programs that are there be kept in place and said there really is "no place like home." She indicated she has diabetes and cancer and desperately needs one good meal a day.

Ken Brown, Chairman, State Board of Aging and Adult Services, stated that this board is a policy making board consisting of seven members from various parts of the state. He explained they have been holding some of their meetings outside of the Wasatch front. He said in conjunction with the board meetings, public hearing were held

where seniors could come and express their concerns. He said they found that meals served in the senior centers were nutritious and in some cases were the only meal some seniors receive. However, many seniors live in areas where centers are not available. He said transportation is a vital need, especially in rural areas. He said they also have concerns about prescriptions drugs. He asked that there be an element of fairness when revenue is allocated.

Pearl Rex Hartzell stated that it seems it takes a lot of gold for these golden years. She gave an example of her neighbor's experience who had to leave their home due to the cuts in meals on wheels and in-home services. She indicated that they had a lovely home and ended up in a "warehouse" nursing home. She said we can't let this happen to people who have served others for many years. She said she appreciated all the good work of the committee and understands the stress they are under to try and stretch limited funds.

Sen. Julander thanked Ms. Hartzell for coming. Sen. Julander said she knew the background of Ms. Hartzell and stated she has given her life to service to children and knows what she is talking about when she talks about service.

Bill Cox from the Utah Association of Counties stated the county governments are charged to provide these programs throughout the state. He said that often the counties are on the short end of finances. He said there is a growing need for these services in many areas. He said they are concerned about the waiting lists, the reduced Medicaid match, the need for drug treatments and mental health services. He stated that treatment saves money in the long run. He said the counties are firm believers in the aging programs. He asked that the committee seriously look at funding levels going to providers in the counties.

Michael Cragun with the Utah Association of Counties said he would like to emphasize some additional points. He said the county commissioners and councils have very seriously taken the suggestions that have come from the Legislature. He said he has concerns about the aging population exceeding the school age population and there will be more people with increased needs every day. He said we need to plan to do everything we can to provide these services. He stated that one day a year this committee gets to hear people come discuss the services they need and how grateful they are for these services, but county commissioners hear from them every day.

Jack Tanner, Executive Director, Utah Behavioral Health Care Network, distributed a packet entitled "Mental Health Funding Crisis - 2004." He said Medicaid rates were of significant concern to the state clear back before 1992. He said the mental health system before that time was fractured, there were multiple providers, there was no accountability for outcomes, no flexibility for effective treatment options, no patient follow up and state costs were escalating. In 1992, a new model was piloted that pooled all funding sources into one location that integrated and coordinated client care. He discussed the two charts in the handout on the impact of FY 2004 Medicaid rate certifications on local mental health programs showing a decline of \$3,252,723. He said people who lose services will end up in emergency rooms, some will be incarcerated and some just won't function.

Pat Fleming, Director, Salt Lake County Division of Substance Abuse Services, distributed a handout showing the process in the treatment of substance abuse. He said the treatment of substance abuse is based on science and includes screening of substance abusers, assessment of biology, psychology and social needs, then the person is placed on a level of care that is matched to their needs. After the treatment plan, they are released to after care with self help groups. The second page of the handout lists the number of hours per week of services for each level of treatment. He displayed a "family cut-out" showing the difference in treatment cost and cost of incarceration. He asked the committee to support S.B. 21 Drug Offenders Reform Act.

MOTION: Rep. Adams moved to approve the minutes of 2-04-04 and 2-05-04. The motion passed unanimously with Rep. Thompson absent at the time of the vote.

The Analysts distributed recommended FY 2004 budget supplementals for the Department of Health and the Department of Human Services which will be discussed on Wednesday.

Stephen Unopulos distributed a copy of a newspaper article telling how he obtained his brain trauma injury in 1964. He said he has fought the consequences of that injury every since and is now an at risk adult. He said he can't cook for himself, is not able to maintain his apartment and has difficulty with everyday activities. He said his mother makes sure he gets an evening meal but she is aging and this won't last. He stated his efforts to work are limited. He said he has been on the waiting list for four years. He asked the committee to please not leave him behind and support funds for traumatic brain disorder.

Deanna Lee said she appreciates what has been mentioned by all the speakers. She said she is 44 years old and has fought learning disorders her entire life. She stated that fourteen years ago she endured a fall which compounded existing difficulties. She said although she lives in her own apartment, she has to live on food that requires no cooking as she cannot cook. She says she also has organization disabilities. She says she has the skills of a child and needs help.

Rebecca Mason, Executive Director, Carbon County Retirement Volunteer Program, said she wanted to give an overview of the program they have for the Senior Corp and why they are seeking additional funding. She said the Senior Corp includes the foster grandparent care program, the senior companion program and the retired and senior volunteer program. The foster grandparents act as mentors, tutors, and care givers for children with special needs. The retired and senior volunteers help with all community problems, in schools, hospitals, libraries, museums or other community agencies. The senior companions assist home bound seniors in paying bills, shopping, helping them get to medical appointments and providing them with contact with the outside world. She said she was here to ask for additional funds for programs and with language that would give the funding flexibility.

Max Young, said as an ex-legislator he would like to speak about each of the programs that Rebecca addressed. He said each of the programs has opportunities for seniors to serve in the community. He said it provides an important vehicle to attract and use the experience and talents of seniors in providing support in a wide range of community activities that effectively serve community areas. He said communities are not just neighborhoods but can extend over wide areas in the counties. He said providing service by volunteer efforts is a low cost approach to getting the job done at the lowest possible cost.

John Harbert, Utah Association of Community Services, said his association is made up of thirty nine private companies all across the state who support people with disabilities. He distributed a handout showing cost cutting strategies over the last three years and the effects of that strategy. He said they had selected one of their members, Kate McConaughy, to tell what life is like within their organization and how they help people and work with the staff she has.

Kate McConaughy, Executive Director, Work Activity Center, said the center is a private non-profit corporation that provides mostly day programs for people with disabilities. She said they currently assist 250 individuals. She explained that like other businesses in this industry, they are facing a crisis. She said revenue from the Division of Service for People with Disabilities has run flat for the last three years. She said that during that same time they have seen an 87% increase in liability insurance, a 17% increase in worker's compensation rates and an almost 100% increase in licensing fees from the state. Since 80% of their budget goes to staffing, she said they have had to be very creative in finding ways to meet these rising costs.

Dr. David Christensen introduced his son Cary who was born normal but suffered massive brain damage and is now 34, but functions mentally at about a 4 year old level. Dr. Christensen stated that as Cary grew, he became more and more aggressive and difficult to control. He said the stress in the home became so great that they placed Cary into the Work Activity Center and into a group home. He is still involved in the group home and needs the independence, but because of frequent staff turnover, he does not have the consistency needed.

Susan Reed stated she has worked about five years at the Work Activity Center. She said she makes \$8 an hour on a 32 hour work week. An example of her budget was distributed and she walked through it for the committee. She

said she is a single parent of two children. She said that due to budget reductions all work weeks have been reduced. She said her parents have helped in the past but are now retired on fixed incomes and cannot do as much. She said she does have insurance through her work but if the cost increases, she will go without insurance and the children will go to the CHIP program. She said she loves her job but needs enough to cover her expenses and have a little extra now and then. Ms. McConaughy stated that 2/3 of her staff is like Susan and things will get much worse if there is no additional funding.

Suzanne Cunningham stated she is an advocate for criminal justice reform. She said she has studied the prisons and drug courts for many years. She said she would like to add her support for S.B. 21. She said that locking people away for drug problems is not the answer. She said the drug courts and treatment will save an amazing amount of money for the state. She said we need to look on drugs as a health issue, not a crime.

Norma Gonzalez stated she moved to Utah from Arizona 2½ years ago with her 27 year old daughter, Nicole, who has spinal bifida and a seizure disorder. She said in Arizona Nicole had a full array of programs. She said when they moved here they immediately signed up with the DSPD program and were put on the waiting list. She said they have been on the waiting list for 2½ years without any indication of when or how to get off that list. She said as she has listened to other family members, she is more and more disturbed that Nicole may be on the waiting list for ten or twelve years. She understands the budget constraints but would just ask for five to ten hours a week. She said maybe the budget should consider partial funding to individuals and not a full range as an option.

Vicky Cottrell, Executive Director, NAMI Utah, said we live in a time of great hope for recovery from mental illness but at the same time the future stability of our critically needed mental health care system is in doubt. She said the most pressing issues are the trends in declining state funding and the increased demands on the treatment providers. She said she is especially concerned about the rural areas and their ability to continue to provide critically needed services. She said critical core service delivery is vital in creating a system where families can stay together and permit people with mental illness to live normal lives. She said recovery is possible but treatment is mandatory.

Stewart Ralphs distributed two handouts on domestic violence and asked for support to appropriate \$50,000 for Domestic Violence in the DCFS budget. He said we are all aware of the problem of domestic violence in our state. He said the handouts address what the money goes for in the shelters. He said last year 2,419 women, 3,639 children, and 20 men were provided shelter services in the state. He said the disturbing figure is that 922 families were turned away from shelters last year because lack of capacity. He reported that Utah is 16th in the nation in domestic violence related deaths. He stated this is a large problem in our society.

Asha Parehk, Director, YWCA, stated that in 2002, 42% of Utah's homicides were classified as domestic violence homicides. She said domestic violence shelters can be life saving alternatives for families caught in the cycle of violence. She reported in the seven months of this fiscal year, the YWCA was not able to shelter 341 families that came asking for help. She said the YWCA shelter operates at close to capacity most of the year. She reported that many people who arrive for help are injured and need medical care and children are most often the innocent victims. She said they are asking that the \$114,000 taken out be returned so they can continue to serve as many families as possible in all of the shelters.

Terri Capener said she is a professional parent and showed a picture of one of her foster daughters. She told of her experience with this child whose mother was ready to abandon her. She said that many times that by the time a child has finally made it off the waiting list, the family has reached the point of burnout and in-home service is not the answer. She said that while people are waiting on the waiting list families are burning out, marriages are dissolving, and families are disintegrating. She said we need to realize that funding affects real people and every child you can reach is a positive move.

Jean Pfaetz said she is a single mother of a 9½ year old boy named Hunter who has been on the waiting list for five years. She said Hunter has autism and is rated as severe. He can not speak but just makes noises and the noises are pretty much continual. She said Hunter relies on a devise called a "touch talker" to communicate. This

device allows him to communicate through a Windows type program with drill down menus. She said it has been a huge help to Hunter and herself. She said the "touch talker" is owned by the school district and she has been trying to purchase one herself. The cost of this device is approximately \$4,000. She said if she had DSPD funding she would not have to live in fear that the school district would take away the talker leaving Hunter without his communication tool.

MOTION: Rep. Thompson moved to adjourn. The motion passed unanimously.

Co-Chair Killpack adjourned the meeting at 4:50 p.m.

Minutes reported by Norda Shepard, Secretary

Sen. Sheldon L. Killpack
Committee Co-Chair

Rep. Jack A. Seitz
Committee Co-Chair